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EXPERIENCES OF CAREGIVERS IN ARRANGING SERVICES FOR SURVIVORS OF TRAUMATIC BRAIN INJURY

by

Jane Elizabeth Smith

A Thesis submitted to the Faculty of Graduate Studies and Research in partial fulfilment of the requirements for the degree of Master of Nursing

Faculty of Nursing

Edmonton, Alberta

Fall, 1998

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ABSTRACT

This descriptive study was designed to document what it was like for caregivers to obtain health care services for survivors of traumatic brain injury (TBI), a group of clients particularly vulnerable to the lack of integration and coordination of services. Interviews were conducted with eight primary caregivers and the following themes were identified following content analysis: the search for information, trust, and understanding; the search for support; the need to speak on behalf of the survivor; and navigating the system. An integrated system of care is one of the major goals of health system restructuring. This study shows that integration of care for TBI survivors has not yet been achieved. Case management has been identified worldwide as one means of improving the integration of health services. The results of this study will contribute to an understanding of the potential contributions of case managers to the care of survivors of TBI and client groups with similar needs.

ACKNOWLEDGEMENTS

Throughout the process of writing this thesis many people have given me encouragement and support. Thank you to Dr. Judith Hibberd for her patience and guidance throughout this study. Thank you also to Dr. P. Giovannetti, Dr. L. Laing, and Professor Donna L. Smith for their advice and assistance with this study.

Thank you to The Northern Alberta Brain Injury Society for their information and support and a special thank you to all of the caregivers who shared their journeys with me.

This thesis is dedicated to my father, John B. Murphy.

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Thesis Overview

Introduction

The problem underlying this research is the lack of integration of necessary health and human services for clients with chronic and complex health needs. Survivors of traumatic brain injury are a client group who will require life long health and human services from a variety of sources and providers. This research is an examination of the experiences of caregivers in arranging health services for family members who have survived traumatic brain injuries.

The achievement of an integrated system of care is one of the major goals of health restructuring. Although some of the structural barriers to service integration have been removed, integration of care for individuals with long-term, complex health and human needs has not yet been achieved. Restructured health delivery systems will succeed only if clients benefit. Case management has been identified worldwide as one means of improving the integration of health services for clients with chronic and complex health needs. It is a dynamic process that depends on ongoing reevaluation of care plans to adjust to changing needs of clients. Client groups most likely to benefit from case management services are those with long-term, chronic conditions and multiple pathologies/diagnoses. Survivors of traumatic brain injury, and their caregivers, are a client group particularly in need of coordination of services over a long period of time. This study was undertaken to explore the experiences of primary caregivers in their role as "case manager" for their family member.

Currently, many individual clients and their primary caregivers are left to manage and coordinate their own care. The expanded role of the family caregiver has become a significant theme in the literature on family caregivers in the past two decades. The physical and psychosocial effects of caregiving on family caregivers have been extensively documented (Boaz & Muller, 1992; Orodenker, 1990; Rutman, 1996; Ward, 1993). However, the experiences of caregivers as they try to arrange health and human services have not yet been explored and documented through research.

Rationale for the Study

The goal of case management is to provide cost efficient and effective care through the coordination of required services. Inherent in this goal is the need to provide support to clients and their caregivers over the duration of care. This study began with a review of the literature on long-term case management. Case management research has focused mainly on program implementation and quality and cost outcomes rather than the process of case management (Bradley, Parette, & VanBiervliet, 1995; Chamberlain & Rapp, 1991; Lamb & Stempel, 1994; Penrod, Kane, Kane, & Finch, 1995; Raiff & Shore, 1993; Rothman, 1992). This has resulted in case management that is practised intuitively rather than on clear principles and best practices (Steinberg, 1994). Yet it is the process that will determine whether or not the outcome is the result of the service provided rather than external variables (Fleishman, 1990).

Clients with complex heath needs require services over an indefinite period of time. Many of these services seem costly and are provided in a system where health services are not yet integrated. Factors influencing the cost-effectiveness of health services include how services are organized, the client group being served, the existing community services, the type of financial support, and existing health policies (Austin, 1983; Clark & Fox, 1993). Cost effectiveness, however, must be viewed in the larger context, rather than the short term, for clients with long-term needs. Early intervention can prevent costly future complications for clients and decrease caregiver stress and physical, emotional, and financial burden. As Clark & Fox (1993) explain, "case management may seem expensive, but it may also reduce the use of expensive resources . . . and pose less economic burden to their families" (p. 469).

Case management is a generic term with multiple definitions depending on the profession, client group, context, and organizational structure (Austin, 1983; Austin & McClelland, 1996; Bower, 1992). When the concept of case management is discussed between professionals, or described in the literature, conceptual and operational difficulties arise. Case management "derives its definition in large part from the nature and needs of a system whose component parts it will be coordinating and integrating

. . . . it must be a creature of its environment, tuned to the specific characteristics and needs of its host system" (Beatrice, 1981, p. 124). Austin (1993) defines case management as "an intervention whereby a human service professional arranges and monitors an optimum package of long-term care services" (p. 452). In a slightly different vein, the American Public Welfare Association describes it as the "brokering and coordination of the multiple social health, education, and employment services necessary to promote self-sufficiency and strengthen family life" (cited in Pearlmutter & Johnson, 1996, p. 179). The Case Management Society of America (1994) describes case management as " a collaborative process which assesses, plans, implements, coordinates, monitors and evaluates options and services to meet an individual's health needs through communications and available resources to promote quality cost-effective outcomes" (p. 60). Geron and Chassler (1994) define case management as "a service that links and coordinates assistance from both paid providers and unpaid help from family and friends to enable consumers with chronic functional and/or cognitive limitations to obtain the highest level of independence consistent with their capacity and their preference for care" (p. v).

Despite the large number of definitions there is common agreement that clients with long-term needs, and their caregivers, require assistance in coordinating care in a system where services are delivered in many different settings and locations. The core components of targeting clients, in-depth assessment, care planning, implementation, monitoring, and reassessment aid in the development of coordinated plans of care that adapt to the changing needs of a client. It is important for health professionals to attain knowledge of the experiences of clients and primary caregivers in their journeys through the health system, and particularly at transition points, so that services can be provided or developed to support the caregiver. This knowledge will contribute to an understanding of the need for, and role of the case manager in the acute care, rehabilitation, and community integration of these client groups.

Approach to the Study

This is a descriptive study in which qualitative research strategies are used to collect and analyse data. Participants in this study are the primary caregivers of a traumatic brain injury survivor. A primary caregiver is the individual who identifies

him- or herself as being responsible for the survivor following the brain injury. Following a pilot study (Smith, Austin, & Smith, 1997) it became evident that the victim had little recall of the events following the accident and therefore it was a family member who assumed the role of arranging services following the injury. Guiding questions in the interviews with caregivers were identified from the literature and the pilot study. Contact with participants was arranged with the assistance of a local brain injury support group. There was an immediate response to the letter of invitation that was mailed to potential participants. Interviews were conducted with eight caregivers. A content analysis was used to identify common themes from the data.

Significance of the study

Family caregivers have become crucial members of the health care team as the availability of needed services and resources decrease. Ideally, family caregivers and health providers, such as case managers, collaborate to plan and coordinate care for the family member with long-term needs, each bringing unique knowledge to the table. Many caregivers become "insider-experts" (Lamb & Stempel, 1994) in their role as primary caregiver. The case manager has knowledge of the client group and services and resources available within the existing health care system. Although the process of case management includes active participation of the client and family members in planning long-term care, obstacles that family caregivers may experience have not been systematically identified.

The life-long needs of traumatic brain injury survivors are costly not only for the health system, but for family caregivers as well. There is a need for research that identifies the areas of support family caregivers require as well as identification of which interventions are most effective with potential client groups.

The need for evidence-based practice and decision making has been identified as an essential component of effective and accountable planning, action and evaluation in health care (Alberta Health, 1995). The findings of this study will contribute to the knowledge case managers require to provide efficient and effective assistance to family members who assume the role of a "case manager" for a family member.

Major Findings

A time frame of one to one-and-one-half hours was allocated for each interview. However most interviews were longer as the caregivers openly described their journeys in search of services and support. Responses to the experiences of caregivers in arranging services were sorted into four major categories: the search for information, trust and understanding; the search for support; the need to speak on behalf of the survivor; and navigating the system. Categories were then sorted in to subthemes of the experiences.

It became obvious that the practical and emotional demands experienced by caregivers had altered their lives irrevocably. All of the caregivers in this study willingly assumed the role of primary caregiver for their family member. Although these caregivers do not seek to relinquish their role as primary caregiver for their family member, they urgently require support from the health care system to enable them to bear the physical, social, and financial costs involved in the provision of care.

Organization of the thesis

This thesis consists of an overview, two manuscripts, and a postscript. The first manuscript is a review of the literature that served as a background for this study. This manuscript has been published (Smith, 1998). The second manuscript is a report of the research written as an article for submission to a journal. The postscript is a more detailed description of the methods used during the research. The results of this study will assist in identifying issues in service integration and policy development for vulnerable client populations, and contribute to the knowledge base required for the development of case management standards and education.

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Experiences of Caregivers in Arranging Services for Survivors of Traumatic Brain Injury: A Literature Review

Introduction

Restructure of the Canadian health system has been driven by an awareness of fragmentation and duplication of services, gaps in service, increasing complexity of delivery systems, fiscal restraint, and limited resources. Restructured health delivery systems will succeed only if clients benefit. Case management is now being used in many countries as a method of integrating and coordinating health and social systems. Client groups most likely to benefit from case management services have complex, long-term conditions and often lack the knowledge and advocacy skills necessary to secure appropriate services.

The majority of articles about case management are found in the American literature. Many of the articles are anecdotal and setting-based, a limitation within this literature. Based on a review of these articles it is evident that the term case management is used in a number of ways. This article is a summary of the identified literature on long-term care case management. The research literature is limited to studies conducted in Canada.

Concept of Case Management

For many clients with long-term disabilities and/or illnesses, the distinction between acute and long-term care is meaningless. Case management provides continuity of care between settings by integrating and coordinating needs and resources around the client. Clients are supported by health practitioners who work proactively (Applebaum & Austin, 1990) with them to achieve quality care with the efficient use of resources. A key aspect of case management is involvement of a case management service over an entire episode of illness/disability or need for service (Smith & Smith, 1997). This person-centred approach emphasizes the importance of the alliance between the case manager and the client. The terms "managed care", "case management" and "care maps" each represent a method of increasing efficiency in the health system and these terms are sometimes used interchangeably. However, there is a distinction between them, as discussed in the following paragraphs.

Managed care is a capitated health funding, systems oriented, approach to health care organized to achieve specific patient outcomes, within fiscally responsible time frames, while using resources appropriate in amount and sequence to specific case types (Spitz & Abramson, 1987). Key aspects of managed care include an emphasis on aggregate rather than coordinated care, financial risk sharing among stakeholders, an administrative structure that manages resources, and gatekeeping to control utilization (McClelland, 1996). Case management is one of the strategies used in managed care organizations. An example of managed care in Canada was the Toronto Hospital's proposed comprehensive health organization (Lamb, Deber, Naylor, & Hastings, 1991).

Care maps, also known as critical paths and clinical pathways, are used in managed care and some case management systems. Limited to a single episode of illness, care maps outline the interventions and the expected client progress within predetermined time frames. Care maps have been prominent in the American health system since the mid 1980s when the New England Medical Centre Hospitals (NEMCH) in Boston developed case management plans (CMP). Eventually multidisciplinary critical paths, abbreviated versions of CMPs which highlight key event and time intervals, were abstracted from the CMPs (Ethridge, 1989; Zander, 1988). Care maps are now also used in the Canadian health system (Ogilvie-Harris, Botsford, & Hawker, 1993; Raiwet, Halliwell, Andruski, & Wilson, 1997).

Case management is a generic term with multiple definitions depending on the profession, client group, context, and organizational structure (Austin & McClelland, 1996; Bower, 1992; Roberts-DeGennaro, 1987). When the concept of case management is discussed between professionals or described in the literature, conceptual and operational difficulties arise. Case management "derives its definition in large part from the nature and needs of a system whose component parts it will be coordinating and integrating . . . it must be a creature of its environment, tuned to the specific characteristics and needs of its host system" (Beatrice, 1981, p. 124).

Despite the large number of definitions, common core tasks, or steps, prevail in all practice settings: Client identification; assessment; care planning; implementation; monitoring; and reassessment. The approach taken in applying these

steps is heavily dependent on the client group, purpose, setting, roles performed, and organizational structure (Austin & McClellan, 1996; Bower, 1992; Geron & Chassler, 1994; Satinsky, 1995)

Client Groups

Clients who need case management services come from all population groups as "different forces contribute to a similar need within different populations" (Rothman, 1992, p. 1). Not all individuals within a target client group require case management services. Client groups requiring case management services include those who are at risk for high health costs, are vulnerable, complex and psychosocial in nature, and/or socially disadvantaged (Austin & McClellan, 1996; Geron & Chassler, 1994). Although case management services are required when individuals are no longer able to coordinate their own services, it does not necessarily mean that the individual must completely relinquish all control of their care to formal and informal caregivers (Seltzer, Ivry, & Litchfield, 1992).

Models of case management

The rapid growth in popularity of case management has resulted in the development of numerous models and frameworks for case management practice. The type of model used is dependent on the professional reference group, authority base, context, target population, and organization (Austin, 1983; Netting, 1992; Rothman, 1992). Applebaum and Austin (1990) identified three classifications of models: broker, service management, and managed care. Brokers serve as a link between consumers and the system, making referrals and allocating services, but do not provide care, allocate funds, or ensure that the client receives the services. Case managers in service management models are fiscally responsible for the care plans they develop, although they may not provide services directly to the client. In managed care models case managers must keep costs below a capitated payment. Providers are prepaid a specific amount and are at risk for any excess costs. Desimone (1988) identified seven types of case management models. These are: social; primary care; medical/social; HMO (Health Maintenance Organization); independent (private) services; insurance; and in-house case management.

Several well-known models have been adapted by organizations to fit their own settings and specific requirements for case management. These include the: Strengths Model (Kisthardt & Rapp, 1992); Generalist Model (Franklin, Solovitz, Mason, Clemons, & Miller, 1994); PACT (Programs in Assertive Community Treatment) Model, originally called the Training in Community Living (TCL) program (Rapp & Kisthardt, 1996); and Rehabilitation Model (Anthony, Cohen, Farkas, & Cohen, 1988).

Hospital case management models by nurses first appeared in the literature in the mid 1980s. Since that time the nursing profession has been intensely involved in developing and implementing nursing case management models. Lamb (1992) identified 3 categories of nursing case management models: hospital based-models; hospital-to-community models; and community based models. More and Mandell (1997) differentiate between "internal" and "external" case management. Models of nursing case management include the: ProACT (Professionally Advanced Care Team) Model (Tonges, 1989); Differentiated Practice Model (Gibson, Martin, Johnson, Blue & Miller, 1994); Tucson Medical Centre Model (TCM) (Olivas, Del Tongo-Armanasco, Ericksen, & Harter, 1989); and Professional Nursing Network (Needs Response) Model (Ethridge & Lamb, 1989).

The Role of Case Manager

The role of case manager provides clients with continuity, consistency, and coordination of care across all clinical settings and boundaries. Case managers "micro-manage" patients' care to ensure desirable outcomes (Smith, Dansforth & Owens, 1994). The role of case manager is influenced by the size and type of case load (Nelson, Sadler, & Cragg, 1995), the degree of fiscal authority (Austin, 1983; Grisham, White, & Miller, 1983), and environmental constraints (Intagliata, 1982).

The role of the case manager requires wide and diverse knowledge and skills. Case managers require advanced knowledge of the client population (Haw, 1995); the ability to recognize and address the unmet needs of clients (Newman, Lamb & Michaels, 1991); and the knowledge to work within existing bureaucratic and organizational service systems (Smith & Smith, 1998). Skills in crisis management, interviewing, communication, teaching, management, collaboration; negotiation, and

innovation (Dinnerman, 1992; Geron & Chassler, 1994; Haw, 1995; Smith, Dansforth, & Owen, 1994) are also a part of the role.

Case management roles include the control and allocation of service resources which can, in a time of fiscal uncertainty and restraint, promote competition between professionals for the power and authority to control and distribute resources. These roles need to be clearly defined to prevent competition between professionals that results in role conflict and "turf" protecting (McClelland, Austin, & Schnick, 1996). The case manager should be the health provider best able to meet the needs of the client. As such, the interdisciplinary team should reflect the complex and diverse needs of the client (Feliciano, 1995).

Case Management Research

Case management research to date has mainly focused on program implementation and quality and cost outcomes rather than the process of case management (Lamb & Stempel, 1994; Rothman, 1992). In a review of outcomes research on case management Chamberlain and Rapp (1991) found only six research studies that described the independent variable (eg. a case management model), defined the dependent variables (client outcomes), and used experimental or quasi-experimental designs. Holloway et al. (1995) reviewed the outcome literature from research studies in the US, Canada, Germany, UK, and Australia from 1987-1993. The authors concluded that case management practice can have an impact on the client's use of services, satisfaction with services, engagement with services, and social networks when delivered with high staff to patient ratios.

Most of the current research is American. This must be carefully evaluated for applicability to the Canadian setting (Korcok, 1994). Eleven Canadian studies have been identified in this literature review. The majority of these studies are in the area of mental health. Goering, Wasylenki, Farkas, Lancee, & Ballantyne (1988) compared a group of clients two years after entry into a case management program with a matched control group of clients not receiving case management services. They found that clients in the case management program had better occupational functioning, decreased social isolation, and no differences in hospitalization rate. Gender differences in social skills, social networks, and housing conditions among homeless

clients decreased after nine months in an intensive case management program (Goering, Wasylenki, St. Onge, Poduchak, & Lancee, 1992). Goering, Farkas, Wasylenki, Lancee, & Ballantyne's (1988) longitudinal study of 70 clients with severe psychiatric disabilities found that more than half of the moderate to severely ill clients showed an ability to improve. Durbin, Goering, Wasylenki, and Roth (1995) used a pre-post test design to evaluate an assertive case management program and discuss five challenges encountered in the study.

The remaining studies are anecdotal in nature. Researchers analysed an organizational change that introduced case management services in an outpatient clinic for clients with schizophrenia in Ontario (Cook, 1995). The importance of the relationship between the case manager and client was identified in a study of 25 homeless women with substance abuse problems in Montreal (Mercier & Racine, 1995) and in a study of 66 participants of an intensive case management program for psychiatric clients in Waterloo, Ontario (Nelson, Sadler, & Cragg, 1995). A retrospective study in a Toronto community mental health case management program found a decrease in hospitalization rates and a decrease in social isolation (Forchuk & Vooberg, 1991). Gender, age, previous addiction, and source of referral were found to be significantly related to receiving advocacy and coordination in 2 addiction treatment programs in Northern Ontario (Graham, Timney, Bois, & Wedgerfield, 1995).

A survey to examine case managers' attitudes toward client directed care in BC yielded a return rate of 57%. Case managers who responded believed that an Independent Provider Program would not improve their client's quality of care and would pose risks of abuse to both the client and attendants. They anticipated more, rather than fewer, job demands (Micco, Hamilton, Martin, & McEwan, 1995). In Edmonton, an exploratory study on care planning showed that case managers from three different professions followed the "norms", or program guidelines, in authorizing services. However, there were differing impressions on what the norms or guidelines were. Authors of this study suggest that the lack of consistency between professionals may result from a lack of standards to ensure equitable distribution of services in care planning (Lemire & Austin, 1996).

Case management research to date remains inconclusive. Comparisons between research results is impeded by weak experimental rigour, a lack of uniformity in measurement instruments, differing independent and dependent variables, the complexity of client needs within the same sample, and lack of operational definitions (Holloway et al., 1995; Intagliata, 1982; Lamb, 1992; Rothman, 1992).

Conclusion

The literature reviewed suggests that case management can lead to the prevention of costly complications, the reduction of duplication and gaps in services, stronger informal support networks, and clients who manage their own care. Further, there is evidence to suggest that case management programs can result in meaningful lives for long-term clients.

Much of the existing research in this area has been descriptive and exploratory in nature. Research to date on case management has focused on program implementation and quality and cost outcomes rather than the process of case management. Clearly, additional research is required on the process of case management, particularly within Canada. Health services must be developed that are client-driven, rather than professionally driven, to address the needs of clients with complex, long-term needs.

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Experiences of Caregivers in Arranging Services for Survivors of Traumatic Brain Injury

The achievement of an integrated system of care is a major goal of health restructure. Although many structural barriers to service integration have been removed, integration of care for individuals with long-term, complex needs has not yet been achieved. For many clients with chronic disabilities and/or illnesses the distinction between acute and long-term care is meaningless as they commonly require both services at the same time. Case management is now being used in many countries as one method of integrating and coordinating care. Client groups requiring case management services include those who are vulnerable, whose problems are complex and psychosocial in nature, who are socially disadvantaged, or who are at risk for high health costs.

Survivors of traumatic brain injury typify clients requiring case management services. The lack of long-term care resources forces many primary caregivers to become informal case managers for their family member. It was assumed that the caregivers in this study would be functioning as lay case managers. The purpose of this study is to gain an understanding of what it is like for primary caregivers of traumatic brain injury survivors to obtain and coordinate services for their family member.

Literature Review

The lives of survivors and their families are forever changed after traumatic brain injury (TBI). In a Canadian study (Parkinson, Stephenson, & Phillips, 1985) the annual incidence of TBI was reported to be 200 cases per 100,000 population. Resources to assist survivors and their families have not "kept pace" with the numbers that are surviving (Direnfeld, 1990). The lack of, or difficulty in accessing long-term rehabilitation services, forces many families to become the primary coordinators, advocates, and caregivers for the brain injured survivor (Florian, Katz, & Lahov, 1989). Many families, ill-equipped to make necessary decisions about care, become overwhelmed and experience high levels of stress (Rosenthal & Young, 1988). Yet studies indicate that the family's ability to provide support for survivors is related to the length and degree of their recovery (Brooks, 1991; Kozoloff, 1987). Although the

effects of head injury on both the survivor and families are well documented (Acorn, 1993; Dring, 1989; Granger, Divan, & Fiedler, 1995) there seems to be little research on the caregivers experiences as they attempt to arrange care and services following the injury.

The function of case management is to facilitate access to services, assure financial accountability, and coordinate services to provide continuity of care rather than fragmented service delivery (Geron & Chassler, 1994; Satinsky, 1995). When a case management service exists case managers work proactively with clients to provide them with appropriate and cost-effective care (Applebaum & Austin, 1990). Although the term "case management" is widely used in the literature it tends to imply that clients are cases who need to be managed and so many health professionals have substituted alternative terms such as care coordination, service co-ordination, and care management (Everett & Nelson, 1992). The term "case management" is used in this study as it is congruent with the literature.

The uncertainty and confusion often associated with health services are reduced as the case manager becomes the primary resource person for the client and/or family (Vourlekis & Greene, 1992). The role of case manager is a critical component of any case management system, serving as a link between the client, the primary caregiver, and the system (Intagliata, 1982). Case managers require both advanced knowledge of the client population and the knowledge and skills to work within existing organizational systems.

Research Method

In this descriptive study qualitative research strategies are used to collect and analyse data. Participants in this study are the primary caregivers of a survivor of a traumatic brain injury that occurred at least 18 months ago. A primary caregiver is the one person who assumes responsibility for the survivor following the brain injury. In this study all primary caregivers are members of the survivor's immediate family. Participants were recruited locally through a caregiver support group for TBI survivors. A letter of invitation was mailed to potential participants and six of the responses to this letter were received immediately. All survivors received care for their injuries in Canada, attended 2-3 health facilities following the accident, and were

residing in the community at the time of the study. Participants have been primary caregivers for 2-9 years and reside in the same community as the survivor. Six female and two male caregivers participated in this study.

Content analysis was used to identify common themes from the data. Nud•ist©, (Nonnumerical Unstructured Data - Indexing, Searching, & Theorizing), version 4, software was used to manage the data during analysis. Initial coding was done by line-by-line analysis of the interviews to identifying relevant words, phrases, and paragraphs within the data. Codes were applied to words, phrases, sentences, or groups of sentences that represented similar themes.

Findings

Responses to the experiences of caregivers in arranging services were sorted into four major categories: the search for information, trust and understanding; the search for support; the need to speak on behalf of the survivor; and navigating the system.

The search for information, trust and understanding

The search for information and understanding began at the time of the accident. The most salient theme arising from the data was the participant's need to receive information when they needed it. Caregivers wanted honest information about their family member's condition, plan of care, and prognosis. Six participants became aware of the seriousness of the injury in the initial telephone call. The other two participants were in the same motor vehicle accident as the survivor and were dependent on emergency staff for initial information about their family member. For example, one caregiver knew "it was going to be really bad" (R3, 16) because her son was airlifted to the hospital. At the hospital caregivers wanted information about the condition of their loved one. As one caregiver explained, "you are in a life and death struggle with your [family member] " (R4, 214). Seven caregivers were told that the prognosis was poor and their family member would probably die in the next 24 to 48 hours. One caregiver suggested that health professionals should emphasize that each brain injury is different rather than describe the prognosis in general terms.

How the information was given also affected how and when the information was received. One caregiver described the doctor as very helpful, talking in

down-to-earth terms about the injury. Other caregivers felt that health professionals were "negative" about the survivor's condition, placing emphasis on the survivor's deficits and poor progress. One caregiver described a conversation with an intern as follows: "He couldn't offer anything. He didn't give me any hope . . . . I said 'Should we be here all the time talking to [my son] and doing stuff?" And he said, "If you want to waste your time being here then you go right ahead ". (R6, 99-101).

Caregivers described the time following the accident as "a blur". Many realized they had been given information about the injury but did not remember it. As one caregiver explained, "you need information, but you're in shock . . . .you're not asking" (R2, 330). Once caregivers had recovered from the initial shock of the injury they wanted more information about the survivor's progress. One caregiver asked her doctor why she had not been given information about brain injury. She was told that as some people are not ready to deal with the information health professionals wait until asked. She replied, "No. You offer [information] to people; they'll know when they're ready and then if they say no, you wait" (R6, 187-188). Some caregivers were handed a pamphlet on brain injury. Although they obtained some answers from such pamphlets, it was left up to the caregivers to follow-up the information. Caregivers needed information in terms they could understand. Although told that the brain had been "bruised" or "damaged", they did not know exactly what that meant. This lack of knowledge was a source of fear and frustration as they tried to find out what the injury involved and what they were now dealing with.

Caregivers did not have one person from whom to obtain information. Instead they talked to a variety of professionals and sought information on their own. As one caregiver summarized, "[The nurses] really tried to get all the information. The doctors were more elusive, they were harder to pin down because they make their rounds and if you're not right there . . . The interns tried, but of course they have limited knowledge too because they are still learning" (R4, 206-209). Another caregiver explained, "You can go through your whole life and never know what a head injury or a brain injury is . . . A broken bone, cancer I can deal with . . . But head injury I knew nothing about, absolutely nothing. And DIDN'T for a long time after this happened because there's nobody to explain to you what it is" (R6, 62-70).

Another caregiver, who lived out of province, had difficulty getting updated information because of always talking to a different health professional at the hospital. In another instance, a doctor explained to a caregiver that seizures sometimes occur following a brain injury, and told her that her husband would be kept in hospital for a few days for observation. As there were no seizures the caregiver did not remember the information. As she explained, "I didn't really know how extensive the injury was at that time. Nobody explained to me that he had a cracked skull . . . and I didn't know enough about brain injuries like that to even ask . . . I think I would have saved myself a lot of trouble later if I had taken the time to ask " (R8, 113-117).

Not withstanding their experiences of information overload and subsequent recollection of information previously forgotten, caregivers perceived that there were times when they were not given vital information. Caregivers expressed anger when recollecting that "nobody told me" about the nature of the injury, the prognosis, the "how to do it" or "what to expect next" in the recovery process. As one caregiver explained about getting information from health providers: "You get it from them, but you've got to drag it out of them. You don't realize they have the information, you don't realize the information that you need, that's the problem" (R5, 558-560). Similarly, "they didn't warn me that he was going to be extremely violent" (R2, 248) and "Nobody had ever told us that somebody who has had a brain injury can develop seizures and epilepsy . . . Nobody prepared me for that" (R7, 215-219).

There was evidence that caregivers did not fully trust the health system to deliver safe and effective services and trust was severely tested in many instances. Baier (1986) defines trust as reliance on another's competence and willingness to look after, rather than harm, a family member entrusted to their care. Trust is not something that can be given lightly, yet caregivers are expected to trust the health system with a family member. One caregiver described a family conference on the survivor's progress as "an exercise for the students . . . . they were asking me questions that I felt were irrelevant . . . . I didn't agree with any of the answers and I didn't have any confidence" (R5, 76-90). Another caregiver explained that she would "run to the store as fast as [she] could to get home [as quickly as possible]" (R1, 592) because of her lack of confidence in home care health providers.

Caregivers were quick to notice changes in the health system following health care restructuring. This also affected the caregiver's trust as "awareness of what is customary, as well as past experience of one's own, affects one's ability to trust" (Baier, 1986, p. 245). One caregiver explained how nurses were no longer able to care for patients as "in the old days" (R6, 574) because of the cutbacks. Caregivers frequently experienced incidents in health facilities that raised their concern for survivors who were unable to protect themselves against harm or injury, further undermining their faith in the system. For example, one caregiver described how his wife became "red and gagging" as water came out of her nose due to an improperly positioned oxygen vaporizer.

Without trust caregivers were reluctant to relinquish care of their family member to the formal health system and tended to maintain long hours in the institution. As one caregiver explained, "you want your loved one taken care of" (R2, 215).

As caregivers accepted the injury they began to "hope against hope" (Morse & Dobernick, 1995). Jevne (1991) describes hope as a part of life's journey, "a relative to courage and trust, an antidote to fear and despair" (p. 147). Caregivers used hope as one coping mechanism to confront the uncertain prognosis. They were sometimes discouraged, not just by the fact of the injury, but also by attitudes of health professionals who did not want to raise "false hope". One caregiver who asked his doctor why he was always so "negative" was told, "we can't go putting your hopes up" (R5, 749).

Caregivers found their own means of maintaining hope. As one caregiver explained: "We'd have all these meetings with the whole care team, and they were always so negative. . . . I think they didn't want to give us false hope, but it almost was the opposite way and it was really depressing that we'd come out and we'd say 'we don't believe them'. And I think that's what kept us going is that hope." (R3, 270-273).

A compassionate and competent approach taken by health professionals can establish a trusting relationship in which information is sought and received. As one caregiver said about a doctor: "I have never met -- I have never encountered anybody

in the health profession who provided as much compassion and just basic good sense as well . . . I must have asked the same question seventy-eight times, and he never made light of my questions" (R1, 77-79).

The need for information continued throughout the recovery process. The difficulty in obtaining information was especially evident in the community as caregivers struggled to arrange services for the survivor following discharge from the formal health system. Instead, caregivers frequently sought information and support from their informal networks.

The search for support

The second theme was the search for support, both formal and informal. In general, the caregivers were not prepared for the long-term effects of the brain injury. Many survivors are left with permanent physical, cognitive, emotional, and/or behavioural disabilities, creating physical, emotional, and financial burdens for caregivers and their families. Primary caregivers have assumed the "brunt of the burden" because of limited services and resources in the community and required support from both professional and informal networks.

Caregivers expressed the need for medical, emotional and practical support when arranging care for their family member. Without support caregivers said they became fatigued, experienced stress, and soon "burned-out". One parent stated, "There [are] a lot of parents out there in [my] situation who have given up. Not because they don't love their child anymore, they just can not cope anymore" (R4, 493-494). He described himself as "just totally burnt" (R4, 497). Some caregivers needed to access the health care system for themselves and, as one stated, "when it gets down to it, in terms of health dollars spent . . . the government has spent more health dollars, on me from this accident than they have on [my husband]" (R7, 425-427).

Informal support networks play a crucial role by filling the voids left by the formal health system. Caregivers noted the importance of emotional support, especially when they became overwhelmed by the situation. As one caregiver stated: "it's the [informal] support systems that are probably more necessary than the medical [systems] . . . . the [informal] support is what is going to make the difference between [emotional] survival or dependency on treating other problems within the medical

system" (R1, 743-745).

Caregivers who were fortunate to have friends or family with a medical background sought guidance and information from them. As one caregiver described, "I actually 'phoned a friend who was in home care and said, 'What do I do?' And she told me what I should do . . .at no time did I feel that anybody [at the rehabilitation centre] felt that I should have some (home care)" (R1, 562-564). Another caregiver was able to ask a friend what to expect next. For caregivers without this type of support the recovery process was more difficult. As one caregiver said, "We knew nothing about home care at that time. We didn't know about respite" (R4, 562).

Family and friends were looked to as a main source of emotional support. The degree of emotional support needed by caregivers seemed to vary. Caregivers often turned to family and friends immediately following the injury. As one caregiver stated, "They kept us going" (R3, 721-726). Although extended family members generally came immediately following the accident they soon had to return home "to get back on with their lives".(R2, 152). As one caregiver explained, "Don't rely too much on your family. Find out what support there is in your family, and how much longer you can expect that support" (R5, 609-611).

Emotional support was crucial as caregivers came to realize the extent of the injury on their family member's personality. They needed to mourn the loss of the person they knew. As one caregiver explained, "it's like living with someone totally different" (R8, 162). Primary caregivers married to the survivor faced the additional stress of changing roles within the relationship. As one caregiver explained, "I don't think it's very different from loss by death, or even divorce. It's a loss" (R1, 349). Although research studies indicate a higher divorce rate following a traumatic brain injury (Florian, Katz, & Lahav, 1989), none of these caregivers considered the option or possibility of divorce. Some caregivers were not supported in their decision by the formal health system. At a family conference one caregiver was confronted with this issue and told to leave her husband now if she was thinking of leaving him.

In addition to professional and social support, the participants' acknowledged the importance of practical support. For example caregivers were quick to identify the support received from their places of employment following the accident. Another

caregiver from out of province received additional support from her friends. For example arrangements were made for the caregiver and her daughter to fly to the other province.

When caregivers did receive support from professionals, the results were perceived as positive. A visit to a psychologist eight years after the injury was described as "the best thing that could have ever happened for me" (R8, 225). During her time with the psychologist, this caregiver began to understand what the injury had done to the brain, and understand that the anger displayed towards her by the survivor was not her fault.

All caregivers reported that they felt relieved once they found out about the existence of local peer support networks. Caregivers found out about support groups from their informal networks rather than from the formal health system. For example, one caregiver found out about a local support group from a colleague at work. It was in this environment that caregivers were able to discuss their fears, find answers to some of their questions, and get support where they felt it was lacking.

The need to speak on behalf of the survivor

The third theme was about advocacy and speaking up for the survivor. Because of the physical, cognitive, and emotional deficits experienced by many survivors of traumatic brain injury, their primary caregivers often assumed the role of surrogate decision maker. Although these caregivers frequently felt the need to speak on behalf of their family member, they were often ill-prepared to act as personal advocates. As one caregiver explained ,"If I knew then what I know now . . . I would have been directly involved and I would have helped plan . . . But then, no. I just followed" (R7, 207-211). Another caregiver felt she would have had a better chance in arranging services if she had "known her rights" rather than accepting what "the system" told her.

Many caregivers felt isolated as they tried to speak on behalf of their family member and often became discouraged in their "battle" with the health system. As one caregiver said, "I did it on my own, and I just felt like I was fighting everybody. I was fighting family because they weren't supportive enough for me. I felt like I was fighting the medical system" (R6, 176-178).

Caregivers watched vigilantly over their family member's care and were quick to notice changes in the survivor's condition. For example, one caregiver "knew" there was "something really wrong" with her husband just prior to his discharge to the rehabilitation hospital. Her knowledge and intuition, developed from having been with her husband constantly, were validated when he needed emergency surgery a few days later. Another caregiver demanded that the staff get a neurologist up to the ward and "do something" (R7, 130) as her husband's condition was deteriorating.

Caregivers also needed to speak out when they disagreed with care provided for their family member. For example, two different caregivers were angry that health providers had not recognized that their family member's behaviour indicated a need to go to the bathroom. In another instance a family caregiver recognized that she had been deceived. A staff member assured her that her son had had his hospital gown changed during the night, but she observed that he was "wearing" the food that he had spilled on himself at supper the night before. Another caregiver expressed her "disbelief" at the rigid adherence to regimes of care in the facilities. She felt they did not take into account the condition of the injured patient. As she explained, "they had a regimen, and I went up one day and they were trying to get him to go to some class, and he could hardly stand he was so tired . . . I found it quite astounding that a family member had to step in to make that kind of a judgement when it was so obvious" (R1, 500-504). Caregivers described how they began to feel that they needed to be present as much as possible to speak on behalf of the survivor. For example, one caregiver described how his wife was fitted for a wheelchair in which the seat was bolted higher on one side than the other. As he explained, " if I wasn't there, what would we have landed up with?"(R5, 468).

Once the survivor was discharged from the Intensive Care Unit caregivers began to question what the next step would be. At that time most caregivers were told that the survivor would be going to rehabilitation. Some rehabilitation facilities were located in the city while another was miles away. Some caregivers were concerned that if their family member was to go to the rehabilitation facility out of the city, this would have limited their ability to watch over, and speak on their behalf. As one caregiver explained, "I wanted him [here], because I wanted to be able to go and visit

him and have family go and see him. These are people with no vehicles, that need to be able to bus over there . . . . I was angry. It's like, why can't you [health providers] do something to help me?" (R6, 392-399).

Caregivers of younger survivors also faced the issue of schooling. When their children were discharged back into the community these caregivers started the process of reintegrating them into the school system. The needs of each child were different and required someone to speak on their behalf within the schools. For example, one school wanted to put the student with special needs children. The psychologist from the rehabilitation facility spoke on behalf of the student to ensure he was placed in a regular classroom rather than a special needs classroom. Another student was integrated into the school to re-learn social skills. This student's parents were able to speak on his behalf to ensure that the goals of returning to school were clearly understood.

Many decisions that caregivers needed to make were in conflict with what the survivor wanted. As one caregiver explained, what survivors wanted is "not always the best thing for [them]" (R5, 233). Another caregiver stated "what's realistic to [my son] isn't realistic" (R2, 1362). Without support in the community caregivers often had to manage the "inappropriate" decisions made by their family member. For example, one caregiver described how her husband had never been offered any help to deal with his anger and frustration. This caregiver therefore arranged for counselling. When the counsellor asked her husband if he needed counselling, he replied "no" and nothing more was done.

Caregivers felt it would have been easier if there had been one person they could have turned to for information and guidance in arranging services. As one caregiver stated, " you need somebody who knows the system because if you don't, you're sunk" (R4, 492). For example, caregivers felt the care was often fragmented and uncoordinated in the community. As one caregiver stated, "The next step was never carried through" (R4). This caregiver sought help as his son's behaviour deteriorated in the community. Each agency he approached was unable to help him and sent him elsewhere. As he explained, " Nobody could help [my son]. It wasn't their responsibility at that time" (R4, 131).

Navigating the system

Several caregivers described their experiences following the injury as a "journey". Throughout their journeys caregivers faced obstacles in the services provided. An obstacle refers to any situation, event, or individual that the caregiver had to circumvent in order for the survivor to receive necessary care. Participants told many stories of how they had to contend with obstacles, and so this final theme was called navigating the system.

One main obstacle was that of not being included or informed as arrangements for services were being made by health care providers. For example, caregivers found themselves disagreeing with the care and treatment plans for their family members. Much of the time this stemmed from not having been informed of why decisions had been made by the health care team. For example, one survivor developed speech problems immediately following orthopaedic surgery, but did not see a speech therapist until four weeks later. As health providers had not explained why there had been a delay in therapy this caregiver, and the survivor, experienced unnecessary anger and frustration. Some caregivers did not know where to voice concerns about the health care system. As one caregiver explained: "The first person assigned to us . . . was way out of his depth. I instinctively knew it, but I didn't know who to complain to, I didn't know what to do" (R1, 840-841).

If the plans made within the formal system did not work as expected, caregivers perceived that they had no alternative but to step-in. One caregiver described her husband's transfer to the rehabilitation centre as follows: "We went to admitting at the [rehabilitation hospital] and we were told that there was no room . . . . I was told I had to take him home . . . . it was a few days, quite a few days . . . . We just take him home, and here's the pills you give him. That was very, very scary " (R1, 409-429).

Although caregivers felt they had been "trained" to look after the family member medically, most felt they lacked the skills to deal with emotional problems. The emotional behaviour of head-injured survivors varied according to the context of the situation and caregivers did not feel they received the support they required to deal with emotional outbursts. For example, one caregiver was told to "phone the police"

when she expressed concern about anger and violent outbursts in public.

As the survivors and their family caregivers journeyed through the health system they experienced transitions in care each time they entered another phase of the recovery period. The first transition occurred when the survivor was admitted to a regular ward or unit from the ICU. This transition was arranged by the institution and there were no identified problems. For most caregivers the second transition occured when the survivor was transferred to a rehabilitation centre from the acute care facility. Although the formal system took responsibility for the timing of this transfer the caregiver dealt with any mistakes or unexpected consequences. It was at this transition that caregivers were first required to speak on behalf of the survivor or express concern over care. The third transition occured when the survivor returned to the community or entered another community agency. Many of the caregivers felt they were on their own at this time and from this time forward.

Transitions in care were much smoother for those caregivers who were able to take a more assertive stance when care arrangements were made. One husband refused to consider a nursing home for his wife as he felt she was going to get a lot better. He told the doctor, "I'm still working, I can't retire like that" (R5, 206). With the assistance of the doctor he applied for self-managed care funding and, after a lengthy period of time, received an offer of financial assistance. Another caregiver's son was admitted to hospital because of uncontrollable seizures. This caregiver had tried unsuccessfully to get assistance in caring for his son in the community. When told his son was ready for discharge, he refused to take him home as "we can't help him properly" (R4, 181). After a three month search, with the assistance of the facility, alternative living arrangements were made.

For other caregivers this transition in care was not as smooth. For example, when one caregiver was told that her son would be discharged back into the community she explained that she had to work and only had a one bedroom apartment. She was then told at a team conference that her son's stay would be extended by one month and that during that time she should make alternative living arrangements. She was told to telephone to arrange for home care services once the survivor returned home.

Once in the community, survivors were mainly reliant on their family caregivers for physical care, transportation, socialization, and financial support. Caregivers, for example, had difficulty finding community living arrangements for their family member. They also experienced difficulty in arranging alternative transportation for the survivor. As one caregiver explained, "It's not easy for him because he's dependent [on me for transportation]" (R6, 480).

Over time, and with experience, most caregivers found a means of navigating the system. One caregiver learned as much as he could about the survivor's medical care. He learned what the medical terms meant and asked if he did not understand the treatment provided. Once he had this knowledge he was able to hold his own in conversations with people in the health system. Other caregivers learned how to be more outspoken. As one caregiver explained, "I learned that you had to fight a lot. You had to. That's sort of the scary thing within the system" (R1, 226-227).

Discussion

Head injuries occur without warning, affecting not only the individual but the family as well. Family caregivers of TABI survivors who were interviewed in this study experienced changes to the family structure that would be life-long and assumed a new role as primary caregiver for the injured family member. The practical and emotional demands experienced by caregivers altered their lives irrevocably. Caregivers endured many stresses and strains, not the least of which was their sense that the health system did not, or would not, provide them with support. Many of the caregivers were unable to "get on with their lives" because their time and energies were taken up with the constant struggle to establish their family member in the community. Several described their journey through the health system "a nightmare" as they attempted to ensure that adequate and safe care was provided for the brain injured survivor.

Speaking of one group of clients of the long-term care system Kane (1994) suggests that dignity and autonomy in long-term care includes "making meaningful choice possible and enabling consumers of such care to retain consistent patterns and values developed over decades of living" (p. 490). The family caregivers interviewed in this study expressed their own needs for meaningful choices and personal

autonomy. For example, one caregiver expressed anger over the difficulty she has had in assisting her son to live independently in the community: "It's not fair to him and it's not fair to me" (R6, 482). The lack of resources has forced her son to continue to be dependent on his caregiver. The caregivers' willingness to assume the role of primary caregiver is done so at great cost to their own personal lives. This raises the ethical and economic question of how much responsibility the health system can expect caregivers to assume at the expense of their own roles in society. By virtue of becoming a caregiver, they become extensions of the client, and require health and human services to assist them in maintaining their multiple roles and responsibilities.

Recent health restructuring has forced families to assume greater caregiving roles for family members with complex, long-term needs. Many caregivers do not have the appropriate knowledge to assume this role and depend on health professionals for information and guidance. The findings of this study illustrate many of the difficulties caregivers encountered in their journey through the health system. Care based solely on the medical model has not adequately met the needs of TBI survivors. (Mann & Dittmar, 1992). Many proponents of health reform have included integrated and coordinated services as a necessary component of efficient health systems. For example, Rachlis and Kushner (1994), strong advocates for health care reform in Canada, argue that "what really needs fixing is the unplanned, uncoordinated, and unaccountable way we deliver health care" (p.3). The results of this study suggest that more needs to be done to promote the integration and coordination of care for client populations with long-term, complex needs such as survivors of TBI.

The main themes of this study, taken individually, have been identified as issues in other studies. For example, the significance of information (Henneman & Cardin, 1992); the impact on the family (Brooks, 1991; Levine, Van Horn, Curtis, 1993); the need for social networks (Halm, 1992); and consumer advocacy (Mann & Ditmar, 1992). Taken together these issues illustrate the lack of integration and coordination of services experienced by survivors in this study. Responsibility for their well-being has fallen to primary caregivers who struggle to manage transitions in care, obtain needed services and, at the same time, met the competing demands of

family and employment.

Fleishman (1990) distinguishes between integrating, or "linking organizations together," and coordinating, or "facilitating resource flows between independent entities." Without integrated and coordinated services primary caregivers of individuals with long-term needs attempt to arrange long-term care in a health care system where resources and services are seldom provided in one location.

Some caregivers described their experiences in the health care system as a journey. Being on a journey usually implies a known destination. For these caregivers, however, it is really a journey with an uncertain destination, requiring transitions as changes in health needs, or life events, affected not only the survivor, but the caregiver as well. For example, child survivors become adults, and adult caregivers become elderly. As one caregiver stated, "I'm scared for me and I'm scared for [my son]. And I don't know who I am more scared for . . . . I could have bailed out. Lots of people do. Statistics will tell you they've bailed out. But I can't. I just can't . . . . . What I want for him is to know that someday, I'm not going to be here forever, he's going to have a reasonably normal life . . . . I believe he can take care of himself, but he needs somebody there [to check on him]" (R2, 1014-1022).

Caregivers need consistent and knowledgeable support as they navigate through the health system. None of the caregivers in this study were able to identify one health provider who had accepted primary responsibility for providing information and assistance in arranging care. This was demonstrated in this study as caregivers described the difficulties they encountered in obtaining information, providing care, and arranging for, and coordinating, services without professional assistance. When difficulties were encountered caregivers faced the daunting task of finding the appropriate resources. As one caregiver explained, "I started out with one agency through the health care system and ended up with three pages of [agencies]. Nobody could help [my son]. It wasn't their responsibility at the time" (R4, 128-130).

Caregivers in this study discussed the behavioural and emotional changes in the survivor over time. This is consistent with research in this area. The greatest recovery occurs in the first six months following the injury (Bond & Brooks, 1976).

Although improvement can continue in the long-term, families reported an increase in emotional changes during the first post-traumatic year (McKinlay, Brooks, Bond, Martinage, & Marshall). These same families, interviewed five years after the injury, identified psychological and behavioural changes as the most frequently reported problems (Brooks, Campsie, Symington, Beattie, & McKinlay, 1986). Caregivers in this study had difficulty in obtaining guidance in managing emotional changes once the survivor was home and experienced increasing levels of stress and caregiver burn-out. Many of the caregivers questioned their ability to continue providing care over the long-term.

Implications

The findings of this study suggest that health professionals and the formal health system did not provide planned, coordinated, and accountable health care for survivors of traumatic brain injury. A salient theme arising from the data was the participant's need for information in a timely manner. Caregivers, however, also need to comprehend and understand the information. Over one hundred years ago Florence Nightingale noted that "Apprehension, uncertainty, waiting, expectation, fear of surprise, do a patient more harm than any exertion" (p. 38). Health care professionals must be sensitive to the needs of family caregivers who are also "clients" of the health care system. Without the information and support they needed, caregivers experienced unnecessary anxiety and wasted many hours attempting to access services and resources.

Ideally, caregivers and health providers, such as case managers, collaborate to plan and coordinate care for the family member with long-term needs, each bringing unique knowledge to the table. Many caregivers become "insider-experts" (Lamb & Stempel, 1994) in their role as primary caregiver. The case manager has knowledge of the client group and services and resources available within the existing health care system. The caregivers who took part in this study agreed that if they had had a resource person, or agency, to help in arranging services it would have eased their journey through the health system. As one caregiver stated, "I don't see how that wouldn't improve the situation, especially in crisis situations . . . . you need someone who knows the system because if you don't you are sunk" (R4, 491-495).

Caregivers require assistance from the formal health care system particularly when experiencing transitions in care. This is not a role for a casual or "novice" health provider but rather for the "expert" (Benner, 1984) practitioner. Case managers, for example, require wide and diverse knowledge and skills to provide clients with continuity, consistency, and coordination of care across all clinical settings and boundaries. The case manager's role has been described as a "travelling companion", who shares the experiences and offers support and assistance, in contrast to a "travelling agent" who only makes the arrangements (Deitchman, 1980). As a companion the case manager can offer aids to navigation as transitions in care occur.

Coordination of formal and informal services and resources between different health settings is a core function of the case management process and will help prevent fragmentation, duplication, and gaps in care (Newman, Lamb & Michaels, 1991; Satinsky, 1995). As a dynamic process, case management depends on continuous reevaluation of care to address the changing needs of clients.

Shortell, Gilles, and Anderson (1994) list four key factors for the development of effective integrated delivery systems: (a) making the system the right size for the population they serve; (b) including population-based health status/needs assessment; © assuming capitated-based risk by integrating physicians into the system, developing the necessary functional support systems, and achieving clinical integration through a comprehensive community care management system; and (d) implementing new management models. For example, Bryan (1996) discusses integrated health services in Canada using a population-based program model whereby members within a population group (eg. traumatic brain injury) require similar services. Bryan suggests smaller areas amalgamate to achieve an adequate population size for efficient services. To achieve integrated health care organizational efforts must be focused on the needs of the people rather than the needs of providers and hospitals. Integrated health services such as this example would provide caregivers with aids to navigating through the health system.

Conclusion

The experiences shared by the caregivers in this study suggest that there was a lack of integration and coordination of health and human services for the family members of participants. Although the small sample size precludes generalization beyond this study, the findings are nevertheless important. The life-long needs of traumatic brain injury survivors are costly not only for the health system, but for caregivers as well. This cost will be significantly raised if caregiver support is lost for even one TBI survivor. Early intervention can prevent costly complications in the future for clients and decrease caregiver stress and physical, emotional, and financial burden.

The research approach used in this study was one in which caregivers of traumatic brain injury survivors were asked directly about their experiences and about what might have helped them as they dealt with the emotional, physical, and practical challenges of caring for their injured family member. Such information is necessary if the formal health and social services systems are to respond effectively to support these and other caregivers of individuals who will need life-long support. The caregivers in this study identified the need for consistent communication and support from a knowledgeable and trustworthy person during episodes of care, particularly at points of transition between programs and service settings. The findings of this study confirm much that has been written about the need for, and role of, a case manager. They also suggest the need for the health system to recognize family caregivers both as partners, and as clients, who need the support of the formal system if they are to continue to meet their caregiver obligations.

Further research with this and other client groups would contribute to role definition for case managers, the identification of gaps in service, the design of needed services, and the identification of duplication and mistakes in service. Increased well-being of survivors and caregivers is one potential benefit, and cost avoidance is another, if improved co-ordination and caregiver support can be achieved.

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Postscript

The purpose of this postscript is to provide further details about the method used, to elaborate on data collection and analysis, and to note the limitations of the study and suggest areas for further research.

Method

Sample

Selection of the sample was purposive (Morris, 1991), in other words, participants were selected according to the needs of the study. Sampling in qualitative research is determined by appropriateness and adequacy. Appropriateness refers to obtaining the best informants available to meet the needs of the study. Adequacy refers to the sufficiency and quality of the data (Morse, 1991). In this study each participant was the primary caregiver of a survivor of brain injury, and was willing to share his or her experience. In qualitative research it is the nature of the experiences of participants that is the object of purposive sampling rather then the total number of people in the sample. The Northern Alberta Brain Injury Society (NABIS) was approached to help identify suitable candidates for the study. The letter of support for the study from NABIS is in Appendix A.

As previously mentioned, survivors of traumatic brain injury (TBI) typify the target groups that require case management services. Their cognitive deficits can range from a coma state in severe injuries (Walker, Kreutzer, & Witol, 1996) to varying degrees of lack of self-awareness, dependent on the severity of the injury (Fleming, Strong, & Ashton,1996). Lack of self-awareness results in a decreased ability to define problems, to propose actions, to justify the proposed actions, and to express feelings (Levine, Van Horn, & Curtis, 1993). Because of the immediate cognitive deficits following TBI it is often left up to the family of the survivors to make decisions during the recovery period. It was therefore the families and caregivers of survivors of traumatic brain injury who were the primary source of data for this study. For the purpose of this study "participant"referred to the primary caregiver of a survivor of TBI.

Participants met the criteria of the study if (a) they had been the primary caregiver of someone who survived a traumatic brain injury at least 18 months ago,

(b) they could speak English, (c) they were willing to share information with the researcher, (d) they had given consent to be part of the study, (e) the survivor received care for the injury in Canada, and (f) the survivor resided in the community or in a long-term care facility at the time of the study. The criteria that the traumatic brain injury occurred at least 18 months ago was to ensure that caregivers have had experience with the health care system.

Data Collection

Following ethical approval (see Appendix B) a letter (see Appendix C) was sent to each family through NABIS inviting them to take part in the study. A response form (see Appendix D) and a stamped, self-addressed envelope was included with each letter. Each participant was contacted immediately upon receiving the response form. The purpose of the study was explained, and inclusion criteria reviewed, and all questions that the caregivers had were answered. An interview time was then established at a convenient place for each participant.

Interviews lasting one to two hour in length were conducted between November, 1997 and January, 1998. All interviews were held at a time and place convenient to the participant in a setting that offered privacy and freedom from interruption. Four interviews were held in the participants' homes and four were held in an interview room at the University because the four caregivers did not want the survivor to know about the interview. After discussing the nature of the research with the participants and after obtaining consent, audio-recorded interviews were conducted with each participant. At the end of the interview the researcher asked permission to contact the participant again in the event that clarification of information was indicated following transcription of the interview data. All audio-recorded interviews were transcribed verbatim by the researcher and checked for accuracy prior to coding. A back-up tape was made in case the initial tape was lost or damaged.

Following consent, and prior to the start of the interview, demographic information (see Appendix E) was gathered to enable the researcher to gain an understanding of the participants. The interview began with the following inquiry: "I am interested in the coordination and continuity of care and services in the health care

system. Let me start by asking about the date of the injury". Open-ended semi-structured questions were used to guide the interview (see Appendix E). The interview was semi-structured to provide the researcher with the opportunity to explore the participant's experiences and to permit a free flow of information.

The research was preceded by a pilot study. The research method proposed for this study was employed for the video "After the accident: A family copes with brain injury" (Smith, Austin, & Smith, 1997). The video was produced for the Case Management Education Project at the University of Alberta, Edmonton, Alberta. The interview was conducted with both the survivor and her mother. It became evident that (a) the survivor had little recall of the events following the accident and that (b) it was the family who had to deal with transitions between institutions. From this pilot study, it was learned that there was a lack of coordination of services for this particular family. The pilot study resulted in the formulation of the guiding questions for this study.

Field notes were also recorded by the researcher immediately following the interview as an added source of data. A journal was maintained to record ongoing insights and concerns throughout the study.

Data Analysis

Data was analysed by content analysis. Content analysis is a research method used to make inferences about text (Weber, 1990). In this study content analysis was used to identify some of the common themes experienced by individuals who care for survivors of traumatic brain injury. NUD•IST© (Nonnumerical Unstructured Data - Indexing, Searching, & Theorizing), version 4, software was used to manage the large amount of data from interview data analysis.

Initial coding was done by intraparticipant microanalysis, or line-by-line analysis, of the interview to identify relevant words, phrases, and paragraphs within the data. Codes were applied to words, phrases, sentences, or groups of sentences that represented similar concepts. Assistance was sought from the thesis chair in coding the first few interviews.

A basic technique of content analysis is the development of a set of categories (Wilson, 1989). A content analysis variable, or category, "is valid to the extent that it

measures the construct the investigator intends it to measure" (Weber, 1990, p. 15). In this analysis the data guided the development of categories. Each category became clearly defined as the data was analysed. Six general themes were initially identified in the data. These were later refined to four themes. The most descriptive exemplars of the data were used to illustrate the findings. Data was continually examined and compared to determine if there was a relationship between the categories.

Methods to assist with the process of analysis included constantly comparing the data, rephrasing questions to clarify perception of the question, discussing ideas with other researchers in the area, drawing back from the data to assist in seeing the whole, and being open to new perspectives as the data was analysed (Downe-Wamboldt, 1992). A written diary was kept by the researcher throughout the data analysis to document changing views of the data, progression of the analysis process, and tentative propositions that emerged from the data.

Rigor

The purpose of qualitative research is to report objectively the perceptions of participants (Morse & Field, 1995). Methodological rigor was assessed using four general criteria: credibility, fittingness, auditability, and confirmability (Guba & Lincoln, cited in Sandelowski, 1986). Confirmability is achieved when the first three criteria are met. Credibility, or truth value, is subject oriented and measures how congruent the research findings are with the informants' perspectives (Morse & Field, 1995). Strategies applied to meet the criteria of credibility included purposive sampling and a review of the themes identified in the study by two other caregivers of survivors of traumatic brain injury. One of these caregivers stated the "lack of information was so frustrating as I tried to make arrangements for my brother in the community. No one was in charge, I had to go to different places and usually got the run around". In addition the researcher kept a personal diary throughout the research process to document decisions, choices, and insights.

The criteria of fittingness, or applicability, is met when a study's findings "fit" contexts outside the study and "fit" the data from which they are derived (Sandelowski, 1986). A study is said to "fit" if the findings reflect both typical and atypical experiences of the phenomena. Reporting of atypical, or negative, cases

ensures that all sides of a phenomena are represented (Morse, 1991). Atypical cases were not deliberately sought outside of the proposed purposive sampling. Approaches to attain fittingness included purposive sampling and examining and reporting typical and atypical factors of the participants' experiences. Affirming that participants had at least 18 months of experience as a primary caregiver ensured that the participants had had enough experience in arranging services in the health system following the injury. Credibility and fittingness were strengthened by having the thesis chair assist in the interpretation of data coding of the first two interviews. The first level coding by the thesis chair was compared with the researchers coding.

Auditability, or consistency, is attained when another researcher can arrive at the same, or similar, conclusions from the data. In qualitative research an audit trail is used to substantiate trustworthiness of the researcher (Rodgers & Cowles, 1993). This is required as qualitative research involves methodological decisions, analytical procedures and researcher self-awareness. The four types of documentation, as described by Rodgers and Cowles (1993), were utilized in this study to document the research process. Contextual documentation refers to the collection of field notes, descriptive accounts of observations and events, and other factors relating to the context of the data collection process. This documentation was used to provide context to the information collected in the interviews. Methodological documentation was used to document the process by which the common themes emerge. Analytic documentation enabled the researcher to retrace the process as data was examined and coded. Personal response documentation was used to minimize bias in the research process. Self-awareness of the researcher is essential to the credibility of a qualitative study throughout the research process. A field journal was kept to monitor personal biases relevant to the study in order to maintain neutrality (Morse, 1991; Rodgers & Cowles, 1993).

Ethical Considerations

The proposal was submitted to the Health Research Ethics Administration Board at the University of Alberta. Informed consent was obtained from all participants involved in the study (see Appendix F). Informed consent included the following: (a) an explanation of the purpose of the study; (b) a description of possible

risks inherent in research as well as benefits that may be obtained; (c) an opportunity to ask questions, and (d) a statement indicating that any questions have been satisfactorily answered. The consent form was assessed by computer to ensure that the grade reading level was no higher than grade eight. An information sheet (see Appendix G) was also given to each participant. This information sheet described the purpose and procedures of the study.

Protection of privacy, anonymity and confidentiality of participants was ensured by the following procedures: (a) Names of the participants are known only by the researcher; (b) Signed consent forms are kept in a locked drawer in an area separate from the audiotapes and typed transcripts; (c) All other forms of data are coded by number to ensure anonymity and contain no data that might identify the participant; (d) Only the researcher and transcriber have listened to the tapes; (e) The transcripts of the interviews have been seen only by the researcher and thesis supervisor; (f) Audiotapes and typed transcripts are kept in a locked drawer; and (g) Tapes will be destroyed after seven years according to University policy. The interview transcripts may be used for further research once ethical clearance is obtained.

A copy of the signed consent form and the information sheet was left with the families who agreed to participate in the study. On completion of the study the researcher provided a summary of the findings to participants who had requested one on the information sheet.

Limitations

The study is limited in several ways. First, the sample consisted of eight participants of one client group who were interviewed only once. Second, the categories identified must be regarded as preliminary as they were not validated by the participants in any subsequent interviews. Finally, generalizations from the findings of this study are unwarrented from such a small sample of participants. However, the data provides many insights into the personal experiences of caregivers and may generate future research questions.

Further Research

Because of the small sample size this study should be replicated within the same target group as well as other long-term client populations. The research interviews should include guiding questions that have arisen from the findings of this study. For example, the impact of the experience of caring for a family member with TBI on the health and well-being of the caregivers should be further explored to examine their use of the health care system for themselves. Such studies would contribute to the development of models of care that will assist health providers, such as case managers, to provide cost efficient and effective care.

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Appendix A

Letter of Support

SEP-04-1997 13:36 NABIS 403 474 4415 P.02/02

NORTHERN ALBERTA
BRAIN INJURY SOCIETY

#102 Royal Alex Place, 10106 - 111 Avenue, Edmonton, Alberta T5G 0B4
TEL: (403) 479-1757 FAX: (403) 474-4415

September 4, 1997

Jane E. Smith
14 Cypress Avenue
Sherwood Park, AB T8A 1J4

Dear Jane:

I have received the copy of your research proposal *Identifying the Need for Case Management for Victims of Traumatic Brain Injury* and am writing to state that I support this research. It is very timely as I have recently begun to explore models of case management and what would be required to implement it in Edmonton. I expect it will be part of the interdepartmental planning for supports and services for survivors of brain injury and their families which is to begin soon with Alberta Health, Family and Social Services and Advanced Education and Career Development and stakeholders, survivors and their families.

I look forward to being associated with your work. We will assist you by inviting potential participants to take part in your research and in any other way we can.

Sincerely,

Nancy Brine

Nancy Brine
Executive Director

Appendix B

Ethical Approval

University of Alberta
Edmonton
Canada T6G 2G4

Faculty of Rehabilitation Medicine
Rehabilitation Research Centre
3-48 Corbett Hall
Director (403) 492-7856 Telephone (403) 492-2903
Fax (403) 492-1626

UNIVERSITY OF ALBERTA HEALTH SCIENCES FACULTIES, CAPITAL HEALTH AUTHORITY, AND CARITAS HEALTH GROUP

HEALTH RESEARCH ETHICS APPROVAL

Date: October 14, 1997

Name(s) of Principal Investigator(s): Jane Smith

Organization(s): University of Alberta

Department: Faculty of Nursing

Project Title: The Experiences of Caregivers in Arranging Services for Victims of Traumatic Brain Injury

The Health Research Ethics Board has reviewed the protocol for this project and found it to be acceptable within the limitations of human experimentation. The HREB has also reviewed and approved the patient information material and consent form.

This approval is valid for one year, with the possibility of extension provided there have been no major changes in the protocol. All protocols may be subject to re-evaluation after three years. Any changes made to the protocol must be submitted to the HREB for approval.

Sharon Warren

Dr. Sharon Warren
Chair of the Health Research Ethics Board

File number: B-12031097

Appendix C

Letter to Participants

Dear (Caregiver):

Your name was given to me by the Northern Alberta Brain Injury Society (NABIS) as someone who has had experience caring for a family member in the health care system. This letter is an invitation to take part in a study about the experiences of caregivers of survivors of Traumatic Brain Injury. The purpose of my study is to gain an understanding of the experiences of these caregivers in arranging needed services. By having a better understanding of these experiences health professionals can improve the care and support they provide.

I am a graduate nursing student interested in understanding these experiences. I am particularly interested in hearing of people's experiences in making transitions from one care location to another.

Should you decide to take part in the study I will arrange to interview you at a time and place convenient to you. During the interview I will ask you to talk about your experiences in the health care system following your family member's injury. If needed, I will contact you for a second interview to make sure I have understood what you were telling me and I may raise new questions. Your responses will be strictly confidential and anonymity will be maintained.

If you are interested in being part of this study or in learning more about it please contact me at (university) (403) 492-8366 or (home) (403) 467-6858 or return the enclosed response form. I have included a stamped, self-addressed envelope for your convenience.

Thank you in advance for your time and consideration.

Sincerely

Jane E. Smith, BScN
MN Nursing Student
Faculty of Nursing
Clinical Sciences Building
University of Alberta
Edmonton, Alberta, T6G 2G3

Appendix D

Response Form

Research Title:	The Experiences of Caregivers in Arranging Services for Survivors of Traumatic Brain Injury.	
Researcher:	Jane Smith RN, BScN	Phone: 467-6858
Thesis Supervisor	Judith Hibberd RN, PhD	Phone: 492-6399

☐ I am interested in participating in the study.

☐ I would like more information about the research .

Name _____

Phone Number _____

Appendix E

Demographic Information

Research title: The Experiences of Caregivers in Arranging Services for Survivors of Traumatic Brain Injury.

Researcher: Jane E. Smith, BScN.

Date:

Date of Injury: _____

Age of survivor at the time of the injury: _____

Your Relationship to the survivor: _____

Number of family members: Adults _____ Children _____

Where did the injury occur ?: _____

Number of Health Care facilities you have been involved with since the injury: _____

Names of the facilities and length of time in each one:

1.

2.

3.

4.

Demographic Summary

Date of Injury:

Injuries occurred between 1989 and 1996

Age of survivor at the time of the accident:

Ages ranged from 15 years to 50 years of age

Relationship of the caregiver to the survivor:

Spouses: 4 caregivers

Parents: 4 caregivers

Where did the injury occur:

Motor vehicle accident: 5

Employment site: 2

At home: 1

Number of health care facilities involved with since the injury:

2 facilities: 6 (Acute care and one rehabilitation facility)

3 facilities: 2 (Acute care and two rehabilitation facilities)

Appendix F

Guiding Questions

1.What can you tell me about your experiences as a caregiver following the injury?

2. What can you tell me about your experience with the health care system once [name] was ready to leave the acute care hospital.

- Where were you sent?
- Why did you go there?
- What information did you need at that time?
- Did you get the information?
- Did you have any help when you transferred to a new location?
- If you did not get any help, who might have helped you?

3. What other health care facilities and programs did [name] attend while recovering from the injury?

- Where were you sent?
- Why did you go there?
- What information did you need at that time?
- Did you get the information?
- Did you have any help when you transferred to a new location? (Coordination)
- If you did not get any help, who might have helped you?
- Do you feel you were involved in decisions that were made regarding (name)'s care?

6. Do you feel that [name]'s personal likes and dislikes were accommodated during the care following the accident?

7. What do you feel were the most difficult things you experienced during the care following the accident?

8 What do you feel were the good things you experienced?

9. If there is one thing that you could change about the care, or care arrangements, what would it be?

10. Would it have helped if one person had been responsible for coordinating (name)'s care?

11. How would this have helped?

Appendix G

Part 1 (to be completed by the Principal Investigator):

Title of Project: The Experiences of Caregivers in Arranging Services for Survivors of Traumatic Brain Injury.

Investigator: Jane E. Smith, BSN
MN Nursing Student
The Faculty of Nursing
3rd floor, Clinical Sciences Building
University of Alberta
Edmonton, Alberta, T6G 2G3
Home (403) 467-6858.
University (403) 492-8036.

Supervisor: Judith M. Hibberd, RN, PhD
Professor
The Faculty of Nursing
3rd floor, Clinical Sciences Building
University of Alberta
Edmonton, Alberta, T6G 2G3
(403) 492- 6399

Part 2 (to be completed by the research subject):

Do you understand that you have been asked to be in a research study?	Yes	No
Have you read and received a copy of the attached Information Sheet?	Yes	No
Do you understand the benefits and risks involved in taking part in this research study?	Yes	No
Have you had an opportunity to ask questions and discuss this study?	Yes	No
Do you understand that you are free to refuse to participate or withdraw from the study at any time? You do not have to give a reason and it will not effect your care of the survivor of traumatic brain injury.	Yes	No
Has the issue of confidentiality been explained to you? Do you understand who will have access to your records?	Yes	No

This study was explained to me by: _____

I agree to take part in this study.

_____ _____ _____
Signature of Research Participant Date Witness

_____ _____
Printed Name Printed Name

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

_____ _____
Signature of Investigator or Designee Date

THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A COPY GIVEN TO THE RESEARCH SUBJECT

Appendix H

Information Sheet

RESEARCH TITLE: The Experiences of Caregivers in Arranging Services for Survivors of Traumatic Brain Injury.

Investigator: Jane E. Smith, BSN
MN Nursing Student
The faculty of Nursing
Clinical Sciences Building
University of Alberta
Edmonton, Alberta, T6G 2G3
Home (403) 467-6858.
University (403) 492-8036.

Supervisor: Judith M. Hibberd, RN, PhD
Professor
The faculty of Nursing
Clinical Sciences Building
University of Alberta
Edmonton, Alberta, T6G 2G3
(403) 492- 6399

PURPOSE: The purpose of this study is to help nurses understand the experiences of families after a family member is the survivor of a traumatic brain injury. I expect that problems, gaps in service, and barriers to living a meaningful life in the community will be identified from this study.

PROCEDURE:

1. The researcher will ask about your experiences in the health care system. The interview will last approximately one hour to ninety minutes.

2. The discussion will be taped. Only the researcher and transcriber will listen to the tapes.

3. The tapes will be transcribed. Only the researcher and thesis supervisor will read the transcripts.

4. All names and other identifying material will be erased from the transcripts of the tapes.

5. The researcher will contact you if clarification of information is required after the tapes are transcribed.

PARTICIPATION: There will likely be no harm to you if you participate in this study, nor will you likely benefit directly from this study. Results from this study may help health professionals help patients and families in planning long-term care.

You do not have to be in this study if you do not wish to be. If you decide to be in the study, you may drop out anytime by telling the researcher. You do not have to answer any questions or discuss any subject in the interview if you do not want to.

Your name will not appear in this study. Only a code number will appear on any forms or question sheets. The researcher will erase your name and any other identifying material from the transcription of the tapes. All tapes, transcriptions, and notes will be kept in a locked cabinet separate from consent forms or code list for seven years after completion of the research, according to University Policy. Consent forms will be kept for at least five years. Data may be used for another study in the future, if the researcher receives approval from the appropriate ethics review committee.

We may publish or present the information and findings of this study at conferences, but your name or any material that may identify you will not be used. If you have questions about this study at any time, you can call the researcher or her supervisor at the numbers above.

REQUEST FOR SUMMARY: (optional)

If you wish to receive a summary of the study when it is finished, please complete the next section:

Name: _____

Address: _____